



Gaining patient experience insights: an integrated and multi-levelled framework of information

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Taking patient experience as a basis, this paper introduces a theoretical framework, to capture insights leading to new technological healthcare solutions. Targeting a recently diagnosed type 1 diabetes child and her mother (the principal caregiver), the framework showed its potential with effective identification of meaningful insights in a generative session. The framework is based on the patient experience across the continuum of care. It identifies insights from the patient perspective: capturing patients' emotional and cognitive responses, understanding agents involved in patient experience, uncovering pain moments, identifying their root causes, and/or prioritizing actions for improvement. The framework deepens understanding of the patient experience by providing an integrated and multi-levelled structure to assist designers to (a) empathise with the patient and the caregiver throughout the continuum of care, (b) understand the interdependencies around the patient and different agents and (c) reveal insights at the interaction level.

Keywords: patient experience, experience design, framework, insights, chronic patient

Introduction

With an increasing life expectancy, healthcare systems around the world have had to evolve to meet several challenges. In the previous century, healthcare was mainly oriented towards reacting to acute pathologies where the focus was to address urgent issues. In recent decades, however, the pattern of pathologies has undergone significant change, with an increase of chronic conditions putting unprecedented stress on healthcare systems (Institute of Medicine, 2001; World Health Organization, 2005).

Chronic diseases are also known as noncommunicable diseases, and include cardiovascular diseases, cancers, chronic respiratory diseases, diabetes or dementia. All these diseases have common characteristics, such as their long duration or their usual non-curable condition. The differences between acute pathologies and chronic diseases are changing the way the healthcare system needs to respond, introducing the concept of a continuum of care (World Health Organization, 2018).

The continuum approach has led to an emerging concept in the healthcare sector: the patient experience. Patient experience refers to the range of interactions that patients have with the different agents of care, such as doctors, nurses and hospital staff, medical consultations, health plans and other medical care facilities. Nowadays, patient experience is regarded as a central outcome for many national health systems (Purcărea, 2016).

In this context, technological solutions are contributing to a wide range of opportunities to improve the patient experience (Andreu-Perez, Leff, Ip, & Yang, 2015). Providing a more personalized, safer, timely,



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efficient and effective experience is becoming a central challenge for the healthcare system (Berwick, Nolan, & Whittington, 2008; Institute of Medicine, 2001).

This approach locates the patient experience in a central position when designing new medical products and solutions (Wechsler, 2018). Such technological solutions can keep patients on the radar and monitor their adherence to treatment, for example.

Altman, Huang and Breland, (2018) made a systematic review of patient centred solution design concluding that there is an inconsistent use of methodologies. They highlighted the need to develop new methods that effectively integrate the most useful components for the healthcare sector. The use of a structured approach to generate new products and solutions with a patient centred approach may be a key factor in their success. Therefore, there is a need to create specific methods and tools for the healthcare sector that help designers design new solutions that take the patient experience as a reference.

While design is a process with different stages (Roozenburg & Cross, 1991), the entire design process is based on identifying meaningful insights that have the capacity to lead to successful new solutions (Caulliraux & Meiriño, 2015). One of the most effective ways to capture such insights is to focus on the customer experience. This is important because it (1) takes the customer perspective, (2) identifies root causes, (3) uncovers at-risk segments, (4) captures emotional and cognitive responses of customers, (5) spots and prevents decreasing sales, and (6) prioritizes actions to improve (McCull-Kennedy et al., 2017; McCull-Kennedy, Zaki, Lemon, Urmetzer, & Neely, 2019). Applying this approach to the healthcare sector, we can focus on capturing insights based on the patient experience with the aim of developing new products and solutions.

This paper presents a framework that enables the identification of meaningful insights based on the patient experience, leading to new products and technological solutions for the healthcare sector.

The framework is based on a literature review of the field of the patient experience. First, we explore the common guiding principles of patient experience, and develop a theoretical framework that integrates different levels of information for capturing meaningful insights. Second, the framework is presented highlighting its potential for empathising, understanding and revealing relevant insights for innovation. Finally, we explore empirically the potential of the framework in a real case study and guide the steps for future research.

Patient experience

Patient experience is a broad and emerging concept. Therefore, its definition is still evolving. The Beryl Institute defines the patient experience as the “sum of all interactions, shaped by an organization’s culture, that influence patient perceptions, across the continuum of care” (J. Wolf, Niederhauser, Marshburn, & LaVela, 2014).

Many authors agree with the “guiding principles” underlined by the Beryl Institute (Purcărea, 2016) such as: engaging all voices in driving comprehensive systemic and lasting solutions; looking beyond clinical experience of care to all interactions and touchpoints; focusing on alignment across all segments of the continuum and the spaces in between; and encompassing both a focus on healing and a commitment to well-being (Silvera, Haun, & Wolf, 2017).

Following this early concept, some authors are rethinking the term patient too. Is it fair to talk about a person with a chronic condition as a patient, knowing that she or he will never be “healthy”? Is it fair to call a patient someone who simply wants to achieve a better state of health? Jones (2013) introduces the term “health seeker”: the health seeker is any person aware of his or her motivation to improve his or her health, whether sick or not. Health seeking is the natural pursuit of one's appropriate balance of well-being.

Therefore, we define patient experience as the sum of numerous multi-agent interactions particularly emotional, as a consequence of the pursuit of health and well-being along the continuum of care, whether sick or not.

Patient experience as a continuum

Patient experience is not just one encounter, but occurs over time and includes many touchpoints; and it is considered as the continuum of care (J. A. Wolf, Niederhauser, Marshburn, & LaVela, 2014). While the patient

experience is built upon diachronic interactions led by different agents and organizations, no agent can oversee the experience like the patient does (Ben-Tovim, Dougherty, O'Connell, & McGrath, 2008).

The patient is the system element that draws a path along the touchpoints; the one who connects all the interactions creating a unique and unbreakable bond, mapping a journey through the continuum of care. These journeys are contingent upon patient needs and the agents involved (Evashwick C., 2005).

The continuum of care has been taken as an axis by different authors in the healthcare discipline, especially when talking about chronic diseases. Batalden et al., (2016) emphasized the idea that the continuum of care for chronic patients goes far beyond mere clinical factors. Patients, seen as co-producers of their own care and attention, live their journey as a continuum, integrating different areas in the healthcare system and other agents present in their life (Figure 1).

The chronic continuum of care leads us to visualize these journeys as more continuous over time and not only based on clinical interactions. Other interactions outside the medical domain are also part of the continuum; for example, tasks related to care or proper adherence to the treatment (Bengoa, 2014) (Figure 1).

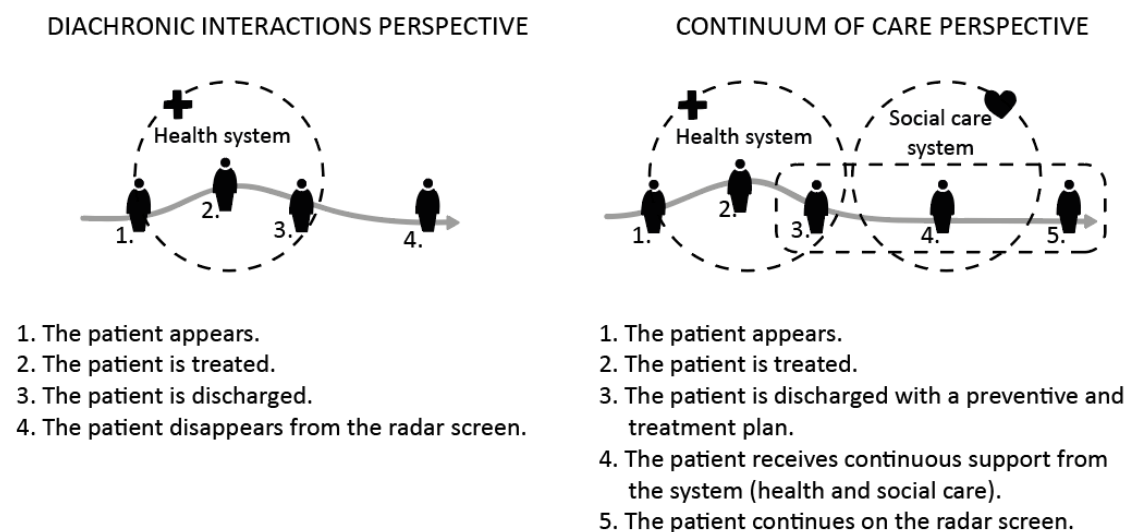


Figure 1: Differences in the patient experience between diachronic interactions and the continuum of care perspective (adapted from Bengoa (2014) and Batalden et al. (2016))

Patient experience as an emotional process

Emotions in patient experience are more relevant than in any other context. Generally speaking, negative emotions are the prevailing trend in the continuum of care (Caulliriaux & Meiriño, 2015). These heightened emotions are elicited due to the threat of losing valued resources, such as well-being, money or time that patients experience. Any threat to these resources is, essentially, a trigger event that gives rise to emotion elicitation (Mccoll-Kennedy et al., 2017).

Chronic diseases appear in an unwanted way: they emerge suddenly in people lives as game changers. Valuable resources such as quality of life, mobility, or similar are threatened by a diagnosis. This creates a dichotomy in the experience, defining a before and after the illness. It has been shown that people who suffer a change derived from a disease, such as diabetes (Isla, Vasallo, Guasch, & Rabasa, 2008), undergo a transition process that may correspond to the psychological stages of grief (Afonso & Minayo, 2013; Kübler-Ross, 1969).

When facing the new situation, patients and family members experience intense emotional reactions throughout the continuum. Those encounters that are especially critical for the patient are commonly known as moments of truth or pain moments (Figure 2). These moments have a more significant influence on experience outcomes than any other encounter (Lemon & Verhoef, 2016). (Variables such as frequency, duration or intensity can be used to describe critical pain moments (Bitran, Ferrer, & Rocha-Oliveira, 2008; den Uijl, Jager, de Graaf, Waddell, & Kremer, 2014).

Patient experience as a multi-agent process

A chronic disease guides the patient through a continuum of care. It integrates a high number of agents, operating within healthcare systems increasingly recognised to be complex (Plsek & Greenhalgh, 2001; Sweeney, Danaher, & McColl-Kennedy, 2015). Each agent operates within a variety of systems as members of internally coordinated procedures that seek the well-being of patients (Ham, Kipping, & McLeod, 2003).

The core driver for healthcare systems should clearly be the improvement of health and the personal experience of health. The prevailing trend, however, is to use disease protocols, financial management strategies and centralised control of siloed programs to manage healthcare systems (Sturmborg, O'halloran, & Martin, 2010).

The World Health Organization described the healthcare system as organizations, people and actions whose primary intent is to promote, restore or maintain health (Musgrove et al., 2000)

This includes efforts to influence determinants of well-being as well as more direct health-improving activities. A patient is likely to draw on a network of resources that extend well beyond the focal organization to include interactions with other agents (Arnould, Price, & Malshe, 2006) such as complementary therapies, interactions with private sources such as peers, family, friends, and even other patients (Black & Gallan, 2015).

For the purposes of this research, there are three different types of agents that are regularly connected through the continuum of care, as identified by the Health Innovation Network (2013) (Figure 2):

- Healthcare, developing activities around “cure” (i.e. doctor).
- Social care, developing activities around “care” (i.e. occupational health).
- The patient ecosystem (i.e. a mother caring for a chronic child).

Healthcare providers are typically managed through policies and plans adopted by the government. The healthcare sector employs several staff working in a professional, usually hierarchical structure and orients its work to patient health following rigorous procedures (Ben-Tovim et al., 2008): doctors, nurses, midwives, paramedics, therapists, psychologists, among others.

Social care is not characterized by standardized management (Anttonen & Sipilä, 1996). It is a care-centred concept, that countenances and develops care as an activity and set of relations situated at the intersection of state, market and family and voluntary sector relations (Daly & Lewis, 2000). As a concept and activity, social care covers a number of different relationships and actors, and it is a broad concept full of different organizations: governmental, private or charitable support organisations.

The patient ecosystem (Gallan et al., 2018) refers to close and affectionate agents to the patient: relatives, friends, colleagues or neighbours. Usually the relationship that exists between the ecosystem and the patient is unpaid care, where the caregiver agent appears. Like the patient, these informal caregivers also experience emotional fluctuations that directly influence their everyday life (Carey, Tennant, Rodgers, & Dodd, 2017) (Figure 2).

Patient experience as a sum of interactions

The continuum of care is a journey for the patient. The patient goes through different encounters with different agents (healthcare, social care or the patient ecosystem) and in different contexts. As the patient moves from interaction to interaction, it is important to understand how such interactions affect the overall experience (Lemon & Verhoef, 2016). Therefore, it is important to describe in detail the ingredients of these interactions.

Each interaction can be described in terms of different factors. On the one hand, interactions can be characterized by the agents present in the encounter and on the other hand, interactions happen in specific contexts, locations and under specific circumstances (Lemon K. & Verhoef P. 2016)

According to Klapperich, Laschke, & Hassenzahl (2018), an interaction can be described with: (1) agents profile (description of the agents that take part), (2) practice (i.e. steps and activities, time-based structure that the agents follow), (3) meaning (i.e. why is this interaction meaningful for the agents?), (4) needs (i.e. which psychological needs are affecting agent wellbeing?), (5) skills (i.e. what skills do the agents use to perform the practice? has the illness affected patient abilities?) and (6) materials (which can be divided into the context or environment, and the materials that agents employ to perform the practice).

This approach is based on (Reckwitz, 2002) social practices work where any interaction consists of three highly interrelated elements: meaning (i.e., symbolic meaning, ideas, aspiration and intrinsic goals), competencies (i.e., skills, know-how and technique) and material (i.e., artefacts, tools, physical context and infrastructures). Experiences are the sum of meaningful moments created by interacting with these material arrangements.

As a conclusion, an in depth understanding of an interaction implies analysing factors related to the context and circumstances of the situation. Figure 2 describes the scope of the interaction, such as agents present in the interaction, the patient abilities and skills, psychological needs, material arrangements of objects, different touchpoints and technologies; and tasks and activities which the agents must perform to reach the goal of the interaction.

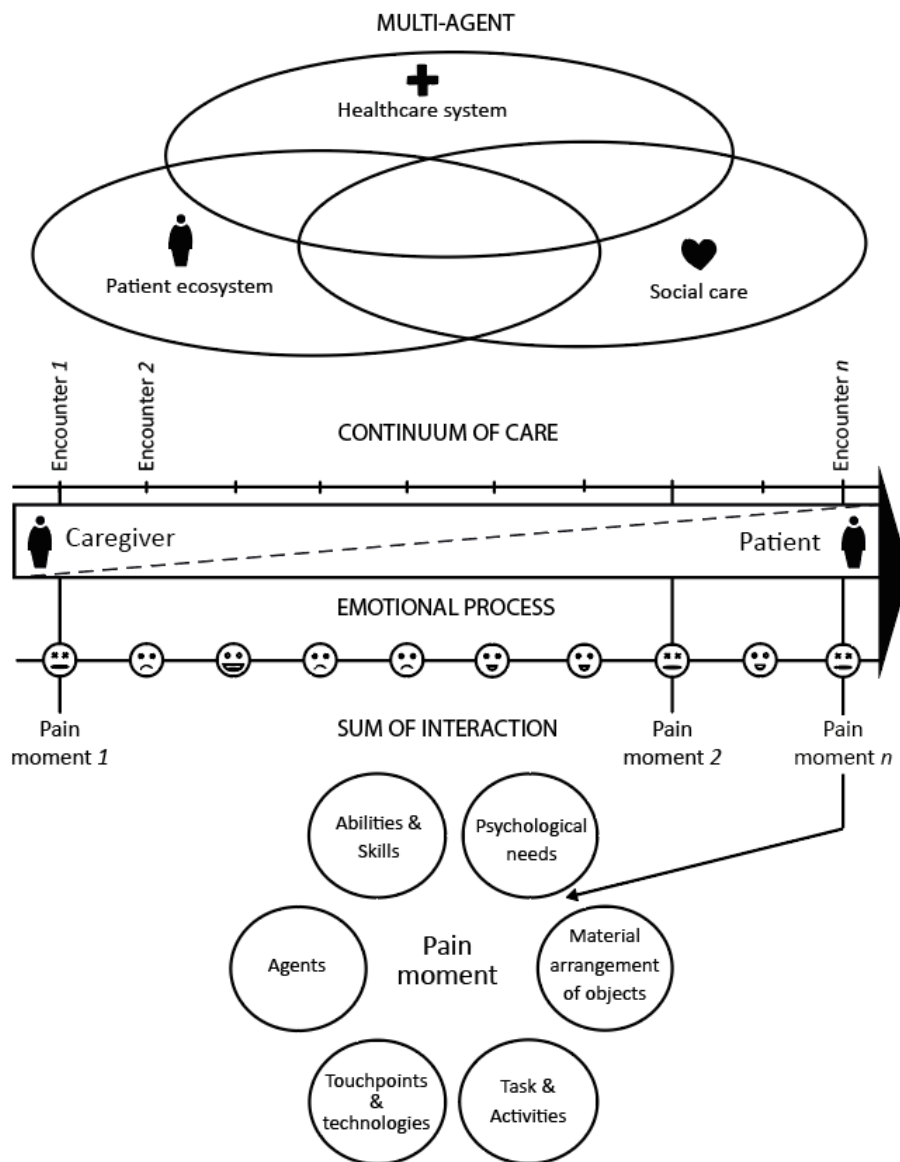


Figure 2: Patient experience features

Methodology

Based on our literature review of the patient experience, we built a theoretical framework to (1) identify significant information regarding the patient experience that enables the capture of design insights and (2) organize information in a multi-level structure to facilitate insight identification.

The framework

We developed a theoretical framework to analyse the patient experience at different levels of information: meso, macro and micro level. The integration of levelled information guided designers to identify relevant and realistic insights (Beirão, Patrício, & Fisk, 2017) revealing technological innovation opportunities that must be used to improve care (Coulter, Locock, Ziebland, & Calabrese, 2014).

Multi-level frameworks encompass different factors that enhance the understanding of an experience (Andreini, Pedeliento, Zarantonello, & Solerio, 2018). By addressing the meso, macro and micro layers of the proposed framework, we visualized the patient experience as a multi-level phenomenon; shaped by emotional, systemic and psychological forces. An integrated view of all relevant factors is needed if designers are to comprehensively understand patient experience.

Linkages between meso, macro and micro levels can guide designers when understanding the full dimension of the patient experience. These connections also provide designers with research guidance when capturing insights that might be relevant for opportunity identification in the healthcare sector (Evans, Higgins, & Hoffer Gittell, 2018; Gallan et al., 2018)

While methods are available for separately addressing each of the levels of the continuum of care (meso, macro and micro) we identified a lack of visualization tools that address the patient experience from a holistic point of view (Curry & Ham, 2010).

To this end, we developed a conceptual framework to visualize information to capture meaningful insights from the patient perspective. The three levels of information visualized in an integrated way are:

1. Meso-level information to empathise: the axis of the analysis is the patient and caregiver journey through the continuum of care. Meso-level analysis involves looking at the patient experience as the key intermediate-sized unit smaller than the healthcare system, but larger than one-to-one interactions. The journey of patients and caregivers is full of information with potential to reveal meaningful insights and opportunities. Many potential new products and solutions will target patients and caregivers themselves, making them the target user. Thus, understanding their routines, emotions and everyday activities is central to identify problems they face and to capture possible insights to solve them.
2. Macro-level information to understand: this level refers to understanding agents present in the patient experience from a system perspective and the interdependencies of how the upper systems function. Studying the largest unit is called macro-level analysis and involves looking at patient experience from a system level. Macro-level analysis is essential for designers to understand how larger system forces affect and shape the patient experience. How agents interplay with each other and how a variety of professionals support patients through the journey is key to identifying specific problems affecting the patient. These professionals may often be target users for specific solutions. An in depth understanding of their working procedures and protocols is a necessary step for revealing meaningful insights in the sector.
3. Micro-level information to reveal: taking patient and caregiver pain moments as a driver, the micro level describes these painful interactions in detail. Micro-level analysis is defined as a focus on individual or small interactions in specific situations. The micro level is important because it focuses on one-to-one interactions occurring through the continuum of the patient journey. The micro level is understood as an in-detail view of the roots of the pain moment and its nuances.

Empathising at a meso level

To empathise with the patient and the caregiver, the meso level has three main factors to be mapped: (1) focusing on the patient and the caregiver, (2) understanding their journey through the continuum of care, and (3) identifying the emotional burden for both of them (Figure 3, meso level).

An important contribution of our framework is to integrate the principal caregiver in the analysis. As the caregiver shares the journey with the patient, the patient's well-being depends largely on his support (Carey et al., 2017). Clinicians frequently overlook the caregiver burden. Identifying pain moments affecting the caregiver, which would otherwise remain hidden, (Adelman et al., 2014) may reveal significant insights that can guide the development of new products and solutions.

To start the analysis, it is important to map chronologically all the interactions that the patient is experiencing through the continuum of care. Moreover, in chronic patients it is crucial to identify those moments that are off the clinical radar. For instance, self-control and self-care moments are important moments to analyse (Telford, Kralik, & Koch, 2006).

This journey is typically characterized by high intensity emotions for both the patient and the caregiver. There are already some design tools like the Customer Journey Map that academic and practitioners use for a better understanding of the entire and chronological experience (Rosenbaum, Otolara, & Contreras Ramírez, 2016). Carey et al. (2017) visualized the patient and caregiver journey through the continuum of care, focusing on their emotions throughout the experience.

Immersive learning increases empathy and understanding of the patient experience (Halton & Cartwright, 2018). Journey mapping allows designers to empathise with the patient and the caregiver experiences to be able to identify critical pain moments throughout the continuum of care (den Uijl et al., 2014). Hendricks, Conrad, Douglas, & Mutsvangwa, (2018) highlighted deep empathy as a key aspect for a better understanding of the problem that contributes to the development of more comprehensive and effective solutions (Yoon, Desmet, & Pohlmeier, 2013).

Understanding at a macro level

The macro-level information analysis seeks to identify the agents involved in the continuum of care, and how they interact with each other. When designing new products and technological solutions, the perspective of different agents is recognised as a core principle that facilitates the process (Hendricks et al., 2018).

On a first level of closeness to the patient, the patient ecosystem includes agents who have a personal relationship with the patient, such as relatives and friends. Unpaid care is a common feature of relationships with these agents (Gallan et al., 2018).

Typically, healthcare agents include healthcare providers that develop activities around “cure” and social care providers that focus on activities around “care”. These professionals respond to their own system with their own goals and hierarchy. This means that each system has its own logic flow of information, resources and economics.

From a patient experience perspective, inefficiencies and overlapping services between agents may arise. These points can present important insights for designers when visualizing opportunities for new products and solutions.

If designers are to identify insights for new products and solutions, it is important for them to consider how these innovations will fit the current systems (Hendricks et al., 2018). Understanding what a new product or solution represents for different agents and the impact it might have on their own functioning logic is a key issue for further acceptance of the innovation within the system.

Accordingly, our framework at a macro level structures information from the healthcare system, social care and the patient ecosystem (Figure 3, macro level).

Revealing at a micro level

The micro level can easily lead to the identification of especially unpleasant interactions in the patient experience. As an example, Ternik, (2016) highlighted the importance of micro level information for effective product innovation. He explored in detail the many considerations to be factored into the design of oral drug products for elderly patients. His research showed that gaining a comprehensive understanding of patient behaviours and needs, and incorporating that knowledge into product design is crucial.

Mullaney, Pettersson, Nyholm, & Stolterman, (2012) explored how human-centred design can expand the solution space surrounding patient experience in healthcare, specifically studying patient emotions. Their findings focused on anxiety in cancer patients and investigated the situational triggers of patient anxiety within the radiotherapy treatment experience, leading to innovation spaces.

Although it is a complex and difficult endeavor, insights can arise when identifying critical interaction throughout the journey (Lemon & Verhoef, 2016). Encounters that are especially critical for the patient are commonly known as *moments of truth* or *pain moments*. Pain moments are endowed with innovative opportunity potential for designers to improve the patient experience (Figure 3) (Desmet, Fokkinga, Ozkaramanli, & Yoon, 2016).

Emotions, therefore, can be seen as elementary information for new product development (Desmet & Hekkert, 2009). A deeper understanding of patient emotions in the pain moment can help the designer to anticipate and therefore minimize the negative impact of such moments.

Every identified pain moment refers to interactions where patients respond to their psychological needs in a specific context and under specific circumstances. Patient abilities and skills play an important role when the patient goes through a certain sequence of activities or tasks to reach the objective of the interaction. Other important factors that characterize interactions are the specific material contexts, objects, technology and touchpoints and the different agents present at the interaction (Hassenzahl et al., 2012; Klapperich et al., 2018).

In this context, at a micro level, our framework integrates information about activities, context, touchpoints, agents, psychological needs and abilities of the patient following the Klapperich, Laschke, & Hassenzahl (2018) approach (Figure 3, micro-level).

The framework

Figure 3 shows the theoretical framework that integrates multi-level information from the patient experience perspective. The framework pre-structures information so that designers can capture meaningful insights for designing new products and solutions in the healthcare sector.

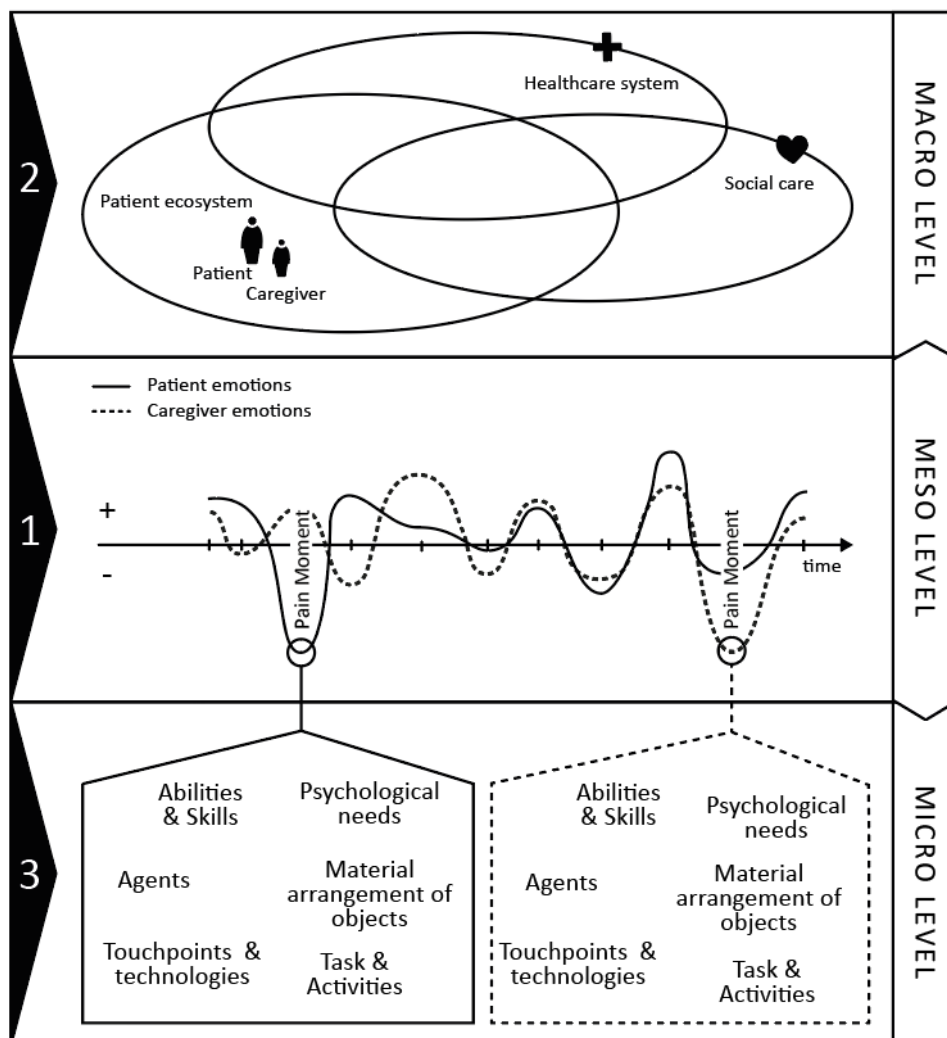


Figure 3: Theoretical integrated and multi-level framework of information

Empirical application of the framework and discussion

The empirical application of the framework targeted the case of a 10-year-old girl with a recently diagnosed Diabetes Mellitus type 1. Diabetes is a chronic disease characterized by hyperglycaemia resulting from defects in insulin secretion, insulin action, or both. The chronic hyperglycaemia of diabetes is associated with long-term damage, dysfunction, and failure of different organs (American Diabetes Association, 2014). The correct development of the treatment for diabetes type 1 is based on the balance of insulin injection, physical activity and controlled diet.

The procedure participants used when testing the framework was: (1) interviews with both the child and her mother, (2) identifying, organizing and plotting relevant information in the framework, (3) a generative session to create ideas and (4) evaluation of the results.

We tested the framework targeting a recently diagnosed type 1 diabetes child and her mother (the principal caregiver). Participants for testing the framework were a strategic designer, a service designer, an interaction designer and a product designer. The interview took place in the Diabetes Association. The mother and the child were selected by the association, due to their active participation in different activities. The mother supports many initiatives to fight for the rights and the improvement of the quality of life of people with diabetes. The child takes part in activities, like summer camps, with other children with diabetes. They are aware of their condition and the adherence to the treatment was adequate.

Interviews with the patient and principal caregiver

The framework informed the structure of the interview script, which focused on the meso, macro and micro levels. This helped the designers to (1) extract relevant information about the journey through the disease experienced by the girl and her mother, (2) identify the participating agents on the journey and understand their function and (3) identify the most critical pain moments and elicit the specifics of the context and situation for pain moments.

The semi-structured interview was made to the mother and conducted by the strategic designer and the service designer: It took 1h. The panel interpret that the mother, as the caregiver, should know more about how the institutions operate. So the interview was more focused on a macro and meso level information gathering. The interaction designer and the product designer interviewed the child, obtaining a broader knowledge at the micro level, by taking detailed painful interactions as the focal point. Finally, a brief summary was made all together, the panel and the interviewees.

It is also important to point out the limitations of interviewing. The panel assumed that what the mother or the child said during the interview could not be the same as what they would say or do in other situation. Despite these limitations, the panel tried to create an atmosphere in which they were likely to talk freely. That is why the interviews took place at the *Diabetes Association*, a familiar place for both. In addition, the panel spent time with them in a meal routine, trying to emulate and observe their day-to-day lives to get a deeper understanding out of that encounter.

Identifying, organizing and plotting

With the analysis of the girl's ecosystem, the designers first identified that the adherence to the treatment regimen was supported by the parents, and the mother was mapped as the principal caregiver. The information provided by the girl and the mother is shown in Figure 4, at the meso level. Plotting the emotions of both of them revealed that the experienced pain moments are not the same for the girl and her mother.

For the mother, the most painful moments were those when the girl needed to manage the treatment on her own: at school or in her leisure time, for example. In contrast, the girl reported different pain moments such as routines and activities dissimilar to those of the rest of the children, or a loss of independency, for instance. The entire journey was described as arduous and overwhelming for the family.

One of the most frequent pain moments was having lunch at school (Figure 4 micro level), where the girl needed to manage her treatment. An in-depth analysis identified that the girl felt overwhelmed by the treatment requirements, and unpopular because she was different to her friends. The mother, on the other hand, worried about her daughter's abilities to manage the treatment on her own. The treatment involved difficult tasks such as glucose control, calculating and injecting the correct insulin dose and estimating the

required number of carbohydrates to eat. Although there were some agents present in this interaction (teachers or canteen monitors), they did not have the knowledge or the responsibility to support the girl.

Designers focusing on the macro level identified different agents that appeared recurrently, for example, the endocrine doctor, the diabetes educator and the diabetes psychologist (healthcare system), the relatives (patient ecosystem) or members of the *Diabetes Association* (social care) (Figure 4, macro level).

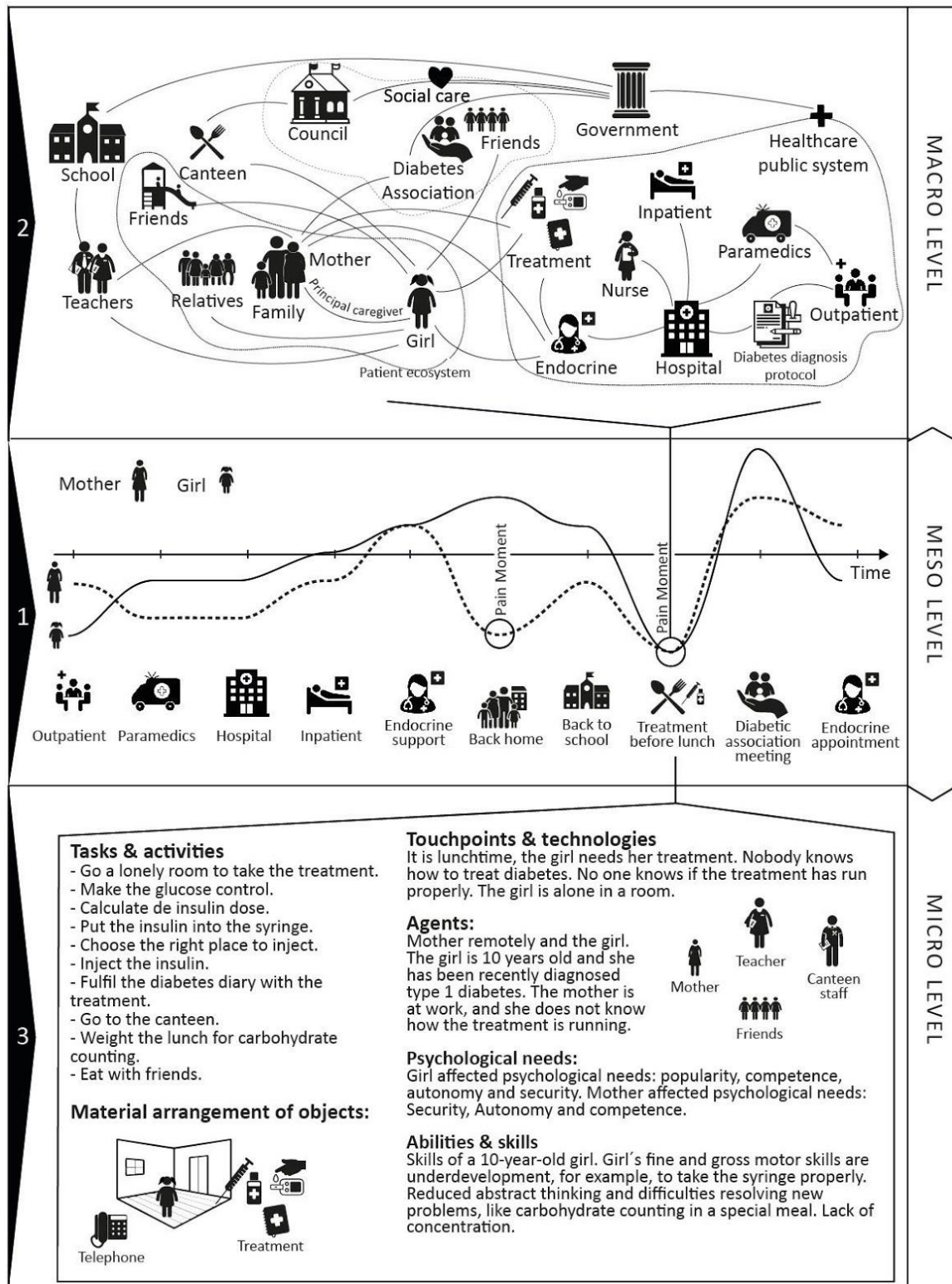


Figure 4: Empirical application of the framework for a recently diagnosed type 1 diabetes child.

Analysing the pain moment “having lunch at school” through the integrated framework, designers were able to understand that the regional education system is not always able to provide healthcare support. On the other hand, the healthcare system does not have the authority to provide healthcare inside the facilities of the school. A further complicating factor was that the canteen service was subcontracted by the council, making inter-agent collaboration even more difficult. Later in the generative session, this revealing insight guided the proposed ideas at the micro level, sharpening feasible proposals.

The integrated framework elicited insights regarding connections and linkages between different information levels in the patient experience, which can be essential for further idea generation in the healthcare sector.

Generative session

After the application of the framework designers proceeded with the identification of insights that led to idea generation. Prioritising pain moments by intensity and frequency, insight identification encompassed the three levels of information and designers were able to create connections among different insights leading to a variety of ideas. This produced a realistic patient analysis base to start creating new solutions that improved the journey.

Five different ideas evolved out of the generative session. These were related to developing skills and/or providing external support to the girl to successfully manage her treatment. Some of the ideas were related to treatment automation, adaption of the treatment devices or the use of information technology.

Evaluation and results

The designers reported that the framework helped to capture patient and caregiver’s meaningful information about their experience at a glance helping to become aware of their condition. The interviews made to fulfil the framework helped to empathise with the child and her mother.

They could easily identify the different pain moments, their intensity and frequency throughout their journey. They highlighted that the structure provided by the framework helped them to gather information during the interviews. Moreover, they emphasized that plotting the information in an integrated way helped them when linking and connecting insights for idea generation.

The panel of designers did agree on most of the positive features of the framework. Nevertheless, one interesting issue arose: It was pointed out that in healthcare-related product design, often solutions find difficult to enter the market, since their existence would mean changing the system.

The strategic designer focused on solving problems in a cross-sectional way, aligning the solutions to an experience-driven approach. This means, instead of focusing on a particular pain moment, she set the focus on the journey’s ups and downs, trying to develop a holistic solution.

The framework facilitated the performance of a detailed analysis of the context, circumstances and agents that intervene in the canteen situation, where the girl needed to manage her treatment. The study of this interaction significantly contributed to the capture of meaningful insights for new products and technological solutions.

The designers, however, found some limitations during the testing. Particularly, they suggested that a more robust framework structure would improve the information gathering process. They proposed supporting the framework with user research tools.

Conclusions

Creating new products and services to improve the patient experience represents a promising field that could greatly benefit from the expertise and contribution of designers and product developers. The complexity of the healthcare sector, however, can pose an important barrier for designers to articulate new feasible solutions (De Sousa Coelho & Branco, 2017), where specific tools and methods for the sector to overcome this barrier are limited. To this end, we presented a framework to support designers in this context.

The framework pre-structures information so that designers conduct qualitative research to gather systematic information aligned with the given theoretical underpinning. It captures meaningful design insights based on the patient experience. After analysis and synthesis, the obtained information is then transformed into insights. These insights are visualised to provide easily accessible representations of the experience (Segelstrom, 2013). Thus, the strength of the proposed framework relies on its integrated approach which

combines, organises and structures different levels of information that are relevant for revealing meaningful insights. When designing for the healthcare sector, designers need to put the patient at the centre of their activities, working towards the best quality of care. Consistent achievement of high-quality care can be guided, therefore, by the patient experience and design (Dixon-Woods et al., 2014; McColl-Kennedy et al., 2019).

The patient experience is at the core of our framework, and this serves as a basis for new products and solutions to be designed. It articulates new solution design pivoting on emotional intensity from the patient perspective throughout the continuum of care (Matheson, Pacione, Shultz, & Klügl, 2015). Another important contribution of the framework is that it integrates the caregiver perspective in the patient experience. Feelings such as anxiety and fear at different levels of intensity are experienced by both patients and caregivers throughout the journey (Carey, Rodgers, Tennant, & Dodd, 2016). Peaks in the intensity level highlight emotional frictions or pain moments, reflecting the disparity between the offered solutions and real patient needs (McColl-Kennedy et al., 2019). Analysing these peaks provides designers with insights to ideate new solutions that can contribute to close this gap.

At a macro level, our framework enables designers to understand the healthcare system and the identification of different agents that influence the patient experience at a certain moment. Different healthcare agents want the same thing: to improve people's health. Unluckily, lack of consensus among agents in a complex system is one of the biggest barriers to innovation (Jones, 2013). Including a macro level perspective is important because potential new solutions may involve changes in healthcare practices, which would have an impact on those agents. Acceptance by professionals, organizations and other agents is a key challenge for the success of new products, which needs to be taken into account when considering different insights.

Finally, designers need to understand the details of interactions within the patient experience so that they can seek innovation. Dealing with information such as the physical context, agents involved or tasks to be performed in an interaction are of significant importance for identifying meaningful insights. Additionally, the micro level of information in our framework refers to information beyond operational and clinical aspects. Factors such as underlying emotions, the psychological needs of different agents in the interaction, or specific patient abilities also need to be taken into account. We believe that these details are of significant value for designers to engage in innovation or new product design (McColl-Kennedy et al., 2019).

It was straightforward to apply the framework to our empirical case. We had the opportunity to evaluate our approach with a real-life chronic patient, and the feedback obtained from the participants was largely positive. The following factors were identified as the main contributions of the framework:

- To capture patient and caregiver's meaningful information about their experience at a glance helps to be aware of their condition. The interviews helped to empathise.
- To identify and understand different agents and their roles supporting patients and caregivers throughout the journey.
- To understand processes and interdependencies among agents when supporting patients and caregivers.
- To understand how new products and solutions link to the psychological needs and skills of patients and caregivers.
- To gather a collection of especially relevant information which supported designers when capturing insights.
- To structure information collected from different domains in an integrated and organized way.

As our testing was limited to a single case, this study has certain limitations. It is complicated to state substantial findings that can be considered representative of the studied framework, which is still at a theoretical stage and comes out of logical argumentation. However, the first performed empirical test has begun to reveal some leads on aspects to improve the methodology: it must conform a space that allows researchers to collect information from a multidisciplinary viewpoint. This means two things. Firstly, each level of the framework should contemplate the possibility to add information from various agents that may operate at different levels. Secondly, the framework should provide researchers with ad hoc tools, and be a support itself which they could use in situ to gather information. Once those improvements are implemented on the framework, further empirical testing would be performed, that would result in the obtention of more reliable data to establish more significant results.

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